Severity of Need Core Services Project

Area Characteristics Panel Final Report

Prepared for:

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SEVERITY OF NEED CORE SERVICES PROJECT

AREA CHARACTERISTICS PANEL FINAL REPORT

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I. Introduction

The Area Characteristics Panel was charged with identifying aggregate characteristics of the State or eligible metropolitan area (EMA) that could be predictive of variations in resource needs for Ryan White Comprehensive AIDS Resources Emergency (CARE) Act HIV/AIDS services. To accomplish this goal, the panel split into three working groups, based loosely on available data sources. The first, the Burden of Disease Group, evaluated ways to measure the number of HIV/AIDS cases in an area and their level of severity using primarily Centers for Disease Control and Prevention (CDC) surveillance data. The second, the Health Infrastructure Group, looked at ways to measure access to health care services using the Area Resource File (ARF) and Health Resources and Services Administration (HRSA) internal data. The third, the Poverty and Census Group, evaluated poverty and aggregate measures of the economic health of an area using variables drawn primarily from the U.S. Census and the Bureau of Labor Statistics.

In general, the Area Characteristics Panel recommended variables that would help enumerate the number of HIV/AIDS cases in an area and then adjust this count based on measures of access, poverty, and insurance. Variables (Table 1) were evaluated based on their importance in determining resource needs for CARE Act services and the current quality, cost, and availability of data used to measure them. Poor access, high poverty, and low rates of insurance may lead to greater need for CARE Act resources to provide services to the needy and to undercounts of HIV/AIDS cases. The Area Characteristics Panel evaluated 20 variables, of which they forwarded 5 for possible inclusion in a severity of need (SON) index.

Table 1.   Variables considered for possible inclusion in an HIV/AIDS SON index, by area characteristics working group

Working Group	Variables Suggested for Use in the SON Index	Variables with Sufficient Rationale for Inclusion but Insufficient Data	Variables with Insufficient Rationale for Inclusion
Burden of disease	• Prevalence of HIV disease	• AIDS-specific mortality • Mortality among all HIV/AIDS patients, adjusted for relative survival	• Sexually transmitted infections
Health infrastructure	• Access to primary care providers	• Number of homeless assistance providers • Number of people without conventional housing	• Hospital location and capacity • HRSA-supported clinics and providers
Poverty and census characteristics	• Percentage below 100% Federal poverty level • Percent with no health insurance • Median household income • Population* *Population is a variable needed to construct rates of other variables. It is not itself a measure of SON.	• Percentage below 200% Federal poverty level • Cost of living adjustment using Federal locality pay adjustment • Cost of living adjustment using regional consumer price indices (CPIs) • Percentage underinsured	• Percent with other forms of insurance • Personal income • Percent unemployed

To prioritize variables, panelists first met as a full group (13 panelists and 2 contractors) to develop a list of variables to evaluate subjectively in terms of each variable's contribution to SON. The group eliminated 12 of 20 variables that were deemed impossible to accurately measure or not related to SON. Panelists were asked to score each remaining variable from 1 to 5, with 1 indicating a variable of the highest importance and 5 indicating a variable of the lowest importance, based on how well each variable measures the theoretical concept of SON. Panelists were also asked to consider that variables may covary or measure the same concept and were asked to prioritize similar variables as opposed to giving them all the same score. These scores were then compiled and the averages ranked (Table 2).

Following the panel's discussions, the list of variables was discussed by a mixed panel of experts, some from this group and some from groups which had discussed other topics, at a two day meeting held in Washington, DC. The mixed group reviewed the list of variable and made recommendations to remove three variables; chlamydia prevalence, unemployment rate, and HRSA-supported clinics.

Table 2   Area characteristics variables forwarded to the full panel and panelists' priority score

	Variable	Average Score
1	HIV/AIDS Disease Prevalence	1.08
2	Poverty Rate	1.69
3	Uninsured Rate	1.77
4	Access to Primary Care Providers	2.62
5	Median Income**	2.62
6	Unemployment Rate*	3.08
7	HRSA-supported Clinics*	3.38
8	Sexually Transmitted Illness (STI) Burden*	4.08

* Removed during the mixed group session.
** Removed during final meeting sessions of the panel.

Panelists in this group generally agreed on the majority of issues they faced. Panelists' votes on these items were remarkably consistent from voter to voter. For example, all but one panelist gave HIV/AIDS disease prevalence a score of 1, all but three panelists gave the poverty rate a score of 1, and only one panelist gave STI burden a score lower than 3. Qualitatively, all panelists agreed that the poverty rate, uninsured rate, and unemployment rate measured similar concepts and should be considered together, although there were some minor differences in whether panelists thought the uninsured rate or the poverty rate was more important to consider.

The panel had some areas of disagreement, which were each resolved before forwarding recommendations to the larger group. First, in the name of parsimony, a subset of panelists believed that the group should forward the smallest possible number of variables to the larger group and suggested the group forward only HIV/AIDS disease prevalence and the poverty rate to the larger group. The larger group disagreed, and the panel's consensus was to forward the eight variables in Table 2. Second, the group disagreed on whether to forward a variable measuring the level of personal income (described below) to the full committee. Arguments in favor of this variable suggested that it was a valuable measure of resources that could potentially be diverted to HIV care. Arguments against this variable suggested that, although the variable did accurately measure income in an area, the total wealth of an area was not descriptive of

wealth that had already been or would potentially be allocated to HIV care. After discussing the issue, the consensus of the group was not to forward the variable.

Finally, one panelist was concerned that the group was paying insufficient attention to measuring aggregate need for substance abuse and mental health services and the burden of sexually transmitted diseases (STDs) and other comorbidities. This panelist also believed that aggregate measures of substance abuse, mental health service use among all people in an area, and rates of STDs in an area were relevant to the need for HIV/AIDS resources. The other members of the panel agreed these issues were important but that (1) individual characteristics, such as STDs and substance abuse, would be covered by another panel and (2) many of these factors were "colinear" with other measures of indigence and lack of care services (e.g., ADAP adequacy, 100 percent poverty level).

Panelists were in strong agreement that the need for substance abuse and mental health services among CARE Act clients indeed would lead to increased resource needs. However, panelists believed the need for substance abuse services was in part measured by the intravenous drug use exposure category forwarded by another panel. Other reliable sources of information to measure these needs among HIV-infected patients were not identified. High rates of STD rates may be predictive of future high rates of HIV and AIDS, and for this reason, these rates may measure the need for future services. However, the relationship between STD infections and new cases of HIV is largely unquantified and likely differs regionally. Furthermore, the primary responsibility of the CARE Act is to provide medical services for those currently diagnosed with HIV and AIDS. Therefore, the panel ultimately thought that aggregate measures of need for services among the entire population (including those without HIV) would not help understand the need for these services among HIV-infected patients.

This report outlines the rationale for recommending each of the variables above and describes variables that were not forwarded for consideration and the reasons these variables were excluded. The format of the report reflects the work of three workgroups:

- Burden of Disease Workgroup, which considered ways to measure HIV and AIDS cases at the community level
- Health Infrastructure Workgroup, which considered measures of an area's capacity to offer access to care
- Poverty and Census Workgroup, which considered measures from the census to measure the underlying poverty in an area.

Each section is divided into two subsections, the first discussing variables that were accepted by the entire group as potential elements for an SON index and the second discussing variables that were not. Each section briefly describes each variable considered and then presents a completed template that guided the evaluation of all variables.

II.   Discussion of Variables

       A. Burden of Disease

Variables considered: prevalence of HIV/AIDS disease, prevalence of sexually transmitted infections, AIDS-specific mortality, and relative survival.

The Burden of Disease Group considered variables that would measure the degree of HIV and AIDS in an area. Current CARE Act allocation algorithms use the 10-year weighted AIDS case count to define the level of disease burden in an area. This group decided to use the cumulative count of living HIV and AIDS cases to measure burden. The workgroup also suggested using reported rates of chlamydia as a possible adjustment to HIV disease rates because higher rates of chlamydia infections may be indicative of a higher degree of incident and potentially unreported HIV cases (Pinkerton et al., 2003).

Variables related to AIDS mortality were not forwarded primarily based on the inadequacy of the data used to measure it. First, deaths are not reported to the CDC with consistent timeliness from all jurisdictions, and second, deaths among patients with HIV/AIDS reported to the CDC may reflect death from any cause. The panel felt that, without adjusting for reporting delays in death rates and the relative survival patterns across jurisdictions, death data would be meaningless at best and potentially misleading at worst.

       1. Variables forwarded for consideration

Prevalence of HIV/AIDS disease: Panelists recommend using the enumerated number of living HIV and AIDS cases per jurisdiction, as reported to CDC surveillance, to measure the SON for CARE Act services. Specifically, the panel recommends using the number of documented living HIV and AIDS cases reported by States using name-based reporting systems in the most recent calendar year.

Current CARE Act allocations are based on the number of estimated living AIDS cases in an area over the past 10 years. The current system excludes HIV cases altogether. In addition, the formula for estimating living AIDS cases includes counts of people who are deceased when a jurisdiction's actual death rate is higher than the national average and excludes individuals who are still alive when a jurisdiction's actual death rate is lower than the national average. The majority of panelists felt that moving from the current system to a system that allocates funds based on living reported HIV and AIDS cases would represent a vast improvement from the status quo.

Further, no previous CARE Act allocations have incorporated CDC HIV information. Currently, HIV disease data are available for only 38 areas and 13 additional areas have a non-name-based reporting system (from which the CDC does not accept data). In addition, variation in completeness of HIV reporting exists across jurisdictions based on the maturity of their name-based surveillance system. Basing allocations on all HIV disease data (inclusive of all HIV and AIDS cases) would reward jurisdictions with the most mature name-based surveillance systems but would not address real differences in underlying need for CARE Act services. However, excluding HIV cases would ignore a substantial element of variation in need between areas altogether.

Unlike other variables considered by the panel, reported HIV was the only variable which certain jurisdictions lacked data by choice. Many States chose to begin reporting HIV data by name following a directive to do so in the previous round of CARE Act legislation. A few areas chose not to report this data. Panelists did not feel that areas that reported HIV cases could be fairly denied funding for those cases simply because other jurisdictions had chosen to not implement similar systems.

The majority of panelists do not recommend adjusting reported AIDS cases to account for additional currently undocumented or unreported cases of HIV in States without mature name-based systems. However, in the event such an adjustment becomes a political necessity, the panel would strongly advise policy makers to convene a scientific panel to investigate the most fair means to make such adjustments.

Group	Item	Example
Descriptive Characteristics	Variable Name	Disease Burden – Prevalence of HIV Disease
	Data Element	Number of unique reported living HIV disease cases in a population.
	Source	National HIV/AIDS surveillance, as reported to the CDC
	Rationale	HIV disease is a measure of the number of people in each are who are presently aware of their conditions and could potentially require medical attention from the CARE Act. For the purposes of measuring resource needs, the following limitations to this rationale should be noted: ▪ Not all patients identified in the surveillance data will use medical care in a given year. ▪ Of those who do use medical care, only a portion will require services provided by the CARE Act. ▪ Some additional patients who are not currently documented HIV or AIDS cases (e.g., those with advanced undiagnosed HIV disease) will require CARE Act services as a result of illness that will not be documented until future years.
	Type of Measure	Direct
	Level of Aggregation	County
	Frequency of Updates	Annual
	Cost	Free
	Availability	A data use agreement(s) was necessary to obtain data for this study. Future use of the CDC's HIV/AIDS surveillance data will require a cooperative ongoing agreement between HRSA and the CDC.

		Reliability	Conceptually, what is measured – the number of diagnosed HIV and AIDS cases reported to the health department – is the same in each surveillance area. However, the across-jurisdiction reliability of AIDS and HIV reporting is different. Reported counts of AIDS cases are measured with a high degree of accuracy across virtually all jurisdictions. The maturity of HIV reporting varies widely by State. Thirteen States do not report HIV data in a form that the CDC accepts, and the number of HIV cases that are captured by the surveillance system varies with the number of years HIV data have been collected in a State, with States with more mature systems documenting greater numbers of cases.
		Validity	Unique cases, as measured by CDC surveillance data, are a highly valid measure of AIDS cases. Studies of AIDS data in most of the United States from 1988 to 1999 indicate most areas have >85% completeness of case ascertainment (Buehler, 1992; Rosenblum, 1992; Schwarca, 1999; Klevens, 2001). Further, all reporting areas routinely update vital status using local vital statistics data, which allows the CDC to identify cases in the system that may have died.
	Quality and Fidelity		However, reported cases of HIV infections are less valid for several reasons. ▪ An estimated 25% of people with HIV disease are not aware of their infection, and this rate of unidentified infection likely varies across jurisdictions in an unknown manner. ▪ The number of cases identified varies substantially based on the maturity of the HIV reporting system. Approximately 25 States have relatively mature reporting systems that likely capture a large proportion of the States diagnosed AIDS cases. Another 13 States have developed reporting systems that are at different levels of maturity and completeness. ▪ 9 States do not report HIV data to the CDC in a manner that the CDC accepts. It will be several years at least before all U.S. jurisdictions report HIV surveillance data that are an accurate measure of actual HIV cases in an area.
		Bias from Measurement Error	▪ Surveillance systems that are less mature tend to have a lower percentage completeness of reporting. ▪ The current surveillance systems do not capture migration of patients to different jurisdictions of residence after diagnosis since the surveillance systems are based on residence at diagnosis. ▪ Bias due to variation in testing practices or access to care (e.g., persons with better access to testing services) is minimal since over time people develop AIDS and are included in prevalence case counts.
		Adjustments Possible	Using total HIV disease cases without an adjustment does not accurately reflect SON, as several States do not report HIV data to the CDC in a manner that the CDC accepts, and several jurisdictions substantially undercount their HIV cases. While a scientifically valid means of adjustment does not exist, practicality and fairness may dictate that such adjustments be made.
		Usability	Neither AIDS data alone nor total HIV disease data are adequate to measure SON at this point. However, using both together provides a better picture of resource needs than any other data source. States that have mature, implemented, name-based HIV and AIDS surveillance systems have systems that quantify the size of their disease burden with a high degree of accuracy. States with newly implemented systems likely will have equally complete data within a matter of years. States that have not implemented name-based HIV and AIDS surveillance systems do not count the number of HIV cases in their

		State accurately, but the level of undercounting is unknown.
	Burden	No. Case counts are reportable now.
Worth	Inclusion	Yes. Summary: HIV disease prevalence is the most desirable measure of the burden of disease in a given population. However, currently the CDC does not accept HIV data from non-name-based reporting areas due to questions about inability to meet national standards for data quality and accuracy and participate in interstate de-duplication. Although disease is undercounted in these States, that is an insufficient reason to prevent the use of the full HIV and AIDS data in States with name-based reporting systems. The panel accepts that this will be unfair to States with new or no HIV name-based reporting system and accepts that adjustments for such States may need to be made. HIV/AIDS cases include AIDS cases from all 50 States and the District of Columbia and HIV cases from States with confidential name-based HIV reporting. Currently, 41 States and 5 Territories report non-AIDS HIV cases to the CDC. Incidence data are not needed to estimate current resource needs because prevalence captures existing as well as new cases of HIV infection. This variable will measure how many people need care now. As the number of cases grows, this will be reflected in the measure.
	Weight	The panel feels that this is the most important variable they are forwarding for consideration and that it should be weighted highly. The resources a given area will need to care for HIV-infected patients are directly dependent on the number of diagnosed HIV-infected cases in an area.

2. **Variables not forwarded for consideration**

Prevalence of sexually transmitted infections: The prevalence of STD infections has been requested from grantees by the CARE Act in the past to assess an area's relative SON. A high level of STDs may indicate a high degree of sexual risk activity that would be predictive of incident HIV infections, although the precise quantitative link between STDs and HIV is not known.

According to the CDC,

> "Individuals who are infected with STDs are at least two to five times more likely than uninfected individuals to acquire HIV if they are exposed to the virus through sexual contact. In addition, if an HIV-infected individual is also infected with another STD, that person is more likely to transmit HIV through sexual contact than other HIV-infected persons. There is substantial biological evidence demonstrating that the presence of other STDs increases the likelihood of both transmitting and acquiring HIV. STDs probably increase susceptibility to HIV infection through two mechanisms: genital ulcers (e.g., syphilis, herpes, or chancroid); and non-ulcerative STDs, such as chlamydia, gonorrhea, and trichomoniasis, which increase the concentration of cells in genital secretions that can serve as targets for HIV. In addition, studies have shown that when HIV-infected individuals are also infected with other STDs, their infectiousness is increased. For example, men with both gonorrhea and HIV are more than twice as likely to shed HIV in their genital

secretions than those who are infected only with HIV"
(http://www.cdc.gov/std/hiv/STDFact-STD&HIV.htm).

Still, the panel questioned whether data on prevalent STD infections were valuable as an indicator of HIV disease that would require CARE Act assistance in light of the fact that the CDC provides direct estimates of the number of prevalent HIV and AIDS cases. Prevention of incident infections was thought to be an important issue to address but one that was ultimately not the central mission of the CARE Act. Of all prevalent STDs, the prevalence of chlamydia was thought by the panel to be the most highly related to HIV disease. This is supported by some evidence (Pinkerton et al., 2003). State-level estimates of chlamydia prevalence are available freely from the CDC, whereas county-specific estimates require a special request from the CDC. The panel suggested using chlamydia rates at the State level as an additional, potentially useful indicator of undiagnosed HIV disease. The panel voted to forward this variable for consideration for use in an SON index but suggested that its weight or value in such an index should be low, if in fact it was included at all.

At the final meeting in Washington, DC, the mixed-group panel questioned the purpose of chlamydia prevalence, and argued in favor of its removal.

Group	Item	Example
Descriptive Characteristics	Variable Name	Disease Burden – Sexually Transmitted Infections
	Data Element	National STD surveillance estimates of prevalent chlamydia trachomatis infections, as reported to the CDC
	Source	CDC, STD (STI) surveillance
	Rationale	Chlamydia may indicate behaviors that result in both STDs and HIV. This variable may be useful as an indicator of communities that may have a high degree of undiagnosed or unreported HIV infection for communities. For example, in communities with newly implemented HIV reporting, a high chlamydia prevalence rate might be indicative of unmeasured cases. The measure could be used to consider upward adjusting the HIV cases of communities that have a high prevalence of both AIDS and chlamydia but a low prevalence of reported HIV infections.
	Type of Measure	Proxy measure of HIV incidence and prevalence.
	Level of Aggregation	Available freely at the State level. County-level data require a request to the CDC.
	Frequency of Updates	Yearly
	Cost	Free
	Availability	CDC; public domain; available at: http://www.cdc.gov/std/stats/default.htm
Quality and Fidelity	Reliability	Chlamydia reported was assessed as "fair" in terms of reliability/quality of detection.
	Validity	Chlamydia is the most commonly reported STD in the United States, with almost 1 million new cases reported per year. Chlamydia reporting reflects recent incidence of STDs and so may reflect recent HIV incidence trends as well, although the degree to which it does is uncertain and may vary across jurisdictions.

		Bias from Measurement Error	(1) Asymptomatic cases lead to consistent underenumeration of actual cases; (2) women are much more likely to be tested than men to such a degree that using only prevalence rates among women may provide more reliable data than using data for both women and men; (3) some differential ability to detect incident cases in different localities.
		Adjustments Possible	CDC researchers adjust reported cases to derive estimated prevalence and incidence; however, these adjustments are applied nationally and may not be helpful for local data (cities that are ordered by their incidence of chlamydia would not change rank order given uniform adjustment).
		Usability	No
		Burden	No
	Worth	Inclusion	Forwarded for consideration as an "adjustment" to HIV/AIDS prevalence
		Weight	Suggest a low weight relative to other variables

AIDS-specific mortality: Mortality resulting from AIDS was considered by the panel as a possible indicator of poor quality of medical care. The panel was concerned that no such estimate of deaths specifically caused by HIV/AIDS exists, only estimates of total deaths from all causes among patients with HIV and AIDS. Aggregate mortality data are fairly good, but patients with HIV disease are at an elevated risk of death from a number of causes, including substance abuse, violence, and accidents. Recently, renal failure and hepatic diseases have become major causes of death among patients with HIV disease. Cause of death information listed on patient death certificates is also not useful because AIDS often may not be listed as a cause of death because of the stigma that is associated with the behaviors that cause AIDS. The degree to which this occurs likely varies across jurisdictions. Without adjusting for these sources of error, the panel felt that the aggregate number of deaths among patients with HIV disease would not be a valid indicator of deaths resulting from HIV or AIDS. The panel also thought that for the purposes of an SON adjustment, AIDS-specific mortality described a variable outside of the scope of the Area Characteristics Panel. The panel forwarded both this variable and a possible adjustment to it (relative survival) to the Patient Coverage Panel for consideration.

During the mixed-group panel meeting in Washington, DC, there was some discussion that including a death rate measure may create disincentives for offering quality care. However, virtually all panelists, including the panelist who raised that point, agreed that a high death rate was at least as indicative of a disenfranchised population that failed to utilize services, a population with a greater number of patients with advanced disease, as it was of a population that lacked access to medical services. The panel noted that even in areas with highly generous Medicaid programs, many disenfranchised patients simply fail to enroll in State programs and therefore lack access to services. The panelists agreed that a measure of deaths among only those with AIDS could be a useful indicator of lack of access and severe case mix and supported the patient coverage group's suggestion to include this variable in the index.

In extended conversation, the patient coverage panel developed a measure of the death rate from HIV and AIDS that could be used as a proxy for either severe case mix, or the failure of patients to receive adequate primary care. That discussion is reflected in that report.

Group	Item	Example
Descriptive Characteristics	Variable Name	Disease Burden – Mortality due to HIV/AIDS-related causes
	Data Element	Aggregate number of deaths among patients with HIV disease
	Source	National Center for Health Statistics (NCHS) Vital Statistics – Mortality data
	Rationale	Enumeration of deaths among patients with HIV/AIDS was evaluated as a possible measure of deaths caused by HIV/AIDS. Areas with a higher number of deaths might have poorer medical services available and therefore greater need for CARE Act services.
	Type of Measure	Proxy measure of deaths caused by HIV/AIDS
	Level of Aggregation	National; could be made available at county-level via interagency data sharing agreement
	Frequency of Updates	Yearly
	Cost	Free
	Availability	Available at county level via data sharing agreement
Quality and Fidelity	Reliability	Random error due to inconsistency in reporting on death certificates. Certificate data allow up to 20 causes of death, but those filling out the certificates may include only immediate cause of death, or all contributing factors, or any number in between.
	Validity	Mortality data from NCHS vital statistics are the gold standard for measuring deaths.
	Bias from Measurement Error	No
	Adjustments Possible	No
	Usability	No
	Burden	Data sharing agreement will be necessary to generate county-level estimates.
Worth	Inclusion	Forwarded to Patient Coverage Panel for consideration
	Weight	Not applicable

Relative survival: Relative survival describes a methodology to adjust raw mortality rates from a given disease, in this case HIV/AIDS, by the mortality characteristics of the areas in which the deceased individuals resided (McDavid et al., 2003). By definition, this variable would always be inferior to an ideally collected measure of mortality caused by HIV/AIDS. The advantage of relative survival is that it can allow HIV/AIDS-specific mortality to be estimated given imperfect collection of the causes of patient death. The panel discussed using this variable to adjust reported mortality of AIDS cases in a given area. This is important because the CDC collects information only on the fact of death and not its cause for patients in the HIV/AIDS surveillance system. In other words, deaths among patients with HIV/AIDS reported by the CDC are from all causes. This issue is not trivial because many patients with HIV disease live high-risk lives and are much more likely to die from such causes as overdoses, homicide, suicide, and acute injuries than the general population, so attributing the raw death rate among them solely to complications of HIV disease could be highly misleading.

The panel was concerned that CDC surveillance data provided an inadequate amount of information from which to apply this adjustment. The panel decided that AIDS-related mortality in general, and relative survival as an adjustment to that rate, were intended to measure the concept of poor quality of health care and therefore were not issues for the Area Characteristics Panel to consider. They forwarded the issue and their research to the Patient Coverage Panel for review. However, the panelists who knew CDC surveillance data the best were highly skeptical that mortality data could be used to indicate deaths caused by AIDS.

Group	Item	Example
Descriptive Characteristics	Variable Name	Disease burden – Relative Survival
	Data Element	Estimates of relative survival of HIV-infected people, generated from life tables, controlling for other causes of death
	Source	(1) HIV Surveillance Data; (2) Age, sex, and race-specific life tables
	Rationale	Measure of death due to HIV/AIDS-related causes, controlling for demographic characteristics and/or other causes of death, estimates death toll directly attributable to disease
	Type of Measure	Statistical estimate generated from life table analysis of mortality data
	Level of Aggregation	National; could be made available at county level via interagency data sharing agreement or via NCHS Research Data Center (RDC)
	Frequency of Updates	Yearly
	Cost	Mortality data accessed via data sharing agreement: free; NHIS Linked Mortality Files available via NCHS RDC: fee involved
	Availability	Mortality data available at county level via data sharing agreement; NHIS Linked Mortality Files available via NCHS RDC
Quality and Fidelity	Reliability	Random error due to inconsistency in reporting on death certificates.
	Validity	Validity not quantified, but assuming problems (noted below) could be overcome.
	Bias from Measurement Error	No systematic bias in mortality data. Absence of institutionalized persons could introduce error into county estimates if size of institutionalized population or prevalence of HIV infection in institutionalized population varies significantly from county to county.
	Adjustments Possible	No adjustments known for reliability/validity bias.

	Usability	(1) Yes – mortality data cannot be used because there is no estimate of the starting population "at risk" – those infected with HIV/AIDS who are eligible to die in the life table. Need starting population plus age-specific death rates by cause of death to generate the life table. (2) Probably – NHIS Linked Mortality Files are mortality data linked to a national health survey; base NHIS data can be used to estimate starting population "at risk," and linked mortality data can be used to generate the life table. However, not designed for county-level analysis; some counties will not be represented in the data, and most counties will not have sufficient sample size for reliable estimation.
	Burden	Fee may be charged to use NCHS RDC to access NHIS Linked mortality data; fairly substantial analytic burden to combine multiple years of data and to generate the life tables that yield the estimates.
Worth	Inclusion	Forwarded to the Patient Coverage Panel for consideration, with caution that Area Characteristics Panel does not think this is a feasible measure
	Weight	Not applicable.

B. Health Infrastructure

Variables considered: access to primary care providers, HRSA-supported clinics, hospital location, homeless assistance providers, and number of people without conventional housing.

The Health Infrastructure Workgroup evaluated the structural capacity of an area to care for patients with HIV and AIDS. They considered variables that evaluated the presence of medical facilities and services to house and assist the indigent, such as housing programs for the homeless. The workgroup thought areas that lacked services would require additional assistance from the CARE Act to serve the patients that lived there.

The workgroup believed that *access to primary care providers* was the best source to measure lack of health care access, because specialty care measures such as *access to infectious disease physicians* were of poorer quality and *hospital location* and the *number of hospitals* primarily measured access to inpatient services, which are not paid for by the CARE Act. The workgroup believed that measures of housing and homelessness were extremely important in measuring patients with the greatest need for CARE Act services but unfortunately could not identify data sources with adequate measures to include in the index.

1. Variables forwarded for consideration

Access to primary care providers: Access to primary care providers measures the ratio of primary care physicians to the general population. Panelists thought it was an important indicator of need because patients may have difficulty obtaining needed outpatient care in areas with provider shortages. Data on the number of primary care physicians are available from HRSA Bureau of Health Professionals, Health Professional Shortage Area (HPSA), and Primary Care Shortage Area (PCSA) databases.

Group	Item	Example
Descriptive Characteristics	Variable Name	Health Infrastructure Systems – Access to Primary Care Providers
	Data Element	Physician/population ratio and/or number of physicians needed to reach adequate level of service (scale of relative need)
	Source	Primary care HPSA database or ARF or PCSA database
	Rationale	Indication of the existing resources in an area or lack thereof
	Type of Measure	Indirect
	Level of Aggregation	County, HPSA area/population, or PCSA
	Frequency of Updates	HPSAs individually updated every 4 years; physician data at the county level usually updated annually
	Cost	Free
	Availability	County-level data and HPSA data available with no restrictions; PCSA data use agreement (DUA) and American Medical Association (AMA) DUA must be evaluated to assess availability
Quality and Fidelity	Reliability	Data are reported by AMA and the American Osteopathic Association. This represents the best available estimates that are thought to be consistent over time.
	Validity	It is a limited measure of service availability, does not include nonphysician providers, and does not capture specialists. **It identifies areas with an absolute shortage of providers as well as some areas that have a shortage of providers who offer services to financially needy patients.** As a result, more rural and fewer metropolitan areas are identified as having shortages, although poor patients residing in some metropolitan areas with many physicians may face quite severe problems with access.
	Bias from Measurement Error	Error is across the board and not specific to a particular area.
	Adjustments Possible	HPSA database adjusts more accurately for actual time in practice and in some cases based on accessibility for low income groups. Others are not easily adjusted.
	Usability	Generally accepted data source
	Burden	No
Worth	Inclusion	Yes
	Weight	To be determined

2. **Variables not forwarded for consideration**

HRSA-supported Clinics: **The variable,** *HRSA-supported clinics,* measures the availability of HRSA-supported service centers that provide HIV care, often financed through the CARE Act. Measuring their availability may be helpful for an SON index, because it would indicate areas

with few services relative to need. Data from this source also can be used to calculate the number of HRSA-supported providers in an area, and this value can be represented as a ratio compared to CDC-reported cases. The mixed group panel recommended the removal of this variable based on an unclear rationale for its inclusion.

Group	Item	Example
Descriptive Characteristics	Variable Name	Health Infrastructure Systems – Availability of Health Care Service Locations
	Data Element	HRSA-supported clinics
	Source	HRSA geospatial warehouse/program and grants offices
	Rationale	Indication of the existing resources in an area or lack thereof for HIV/AIDS patients and/or prevention/testing services
	Type of Measure	Direct
	Level of Aggregation	Local address; could be aggregated to county or area level
	Frequency of Updates	Quarterly updates to warehouse
	Cost	None
	Availability	No restrictions
Quality and Fidelity	Reliability	Grantee data are solid; actual site locations are less reliable but still accurate at the EMA and State levels
	Validity	It is a limited measure of service availability; does not include types of services offered, size of operation, etc. May exclude some types of delivery sites (health departments) due to lack of data.
	Bias from Measurement Error	Error is across the board and not specific to a particular area.
	Adjustments Possible	No
	Usability	Not aware of any issues
	Burden	Not aware of any issues
Worth	Inclusion	No
	Weight	To be determined

Availability of health care services: The location of hospitals was at first thought to be a potentially useful indicator of health care access. However, given that the CARE Act does not reimburse inpatient services and that measures of primary care providers and CARE Act supported clinics are available, the additional value of hospital location as an indicator of access is low.

Group	Item	Example
Descriptive Characteristics	Variable Name	Health Infrastructure Systems – Availability of Health Care Services Locations
	Data Element	Hospital locations
	Source	HRSA geospatial warehouse
	Rationale	Indication of the existing resources in an area or lack thereof for HIV/AIDS patients and/or prevention/testing services
	Type of Measure	Direct
	Level of Aggregation	Local address; can be aggregated to county level
	Frequency of Updates	Quarterly updates to warehouse
	Cost	None
	Availability	No restrictions
Quality and Fidelity	Reliability	American Hospital Association data are the best source available.
	Validity	It is a limited measure of service availability; does not include types of services offered, size of operation, etc.
	Bias from Measurement Error	Error is across the board and not specific to a particular area.
	Adjustments Possible	No
	Usability	No known issues
	Burden	No
Worth	Inclusion	No
	Weight	Not Applicable

Homelessness: Homelessness was thought by the subpanel to be highly related to the need for CARE Act services, as HIV prevalence is extremely high among the indigent poor and these patients have low access to medical services. In addition, in many communities, persons living with HIV and AIDS are at increased risk for homelessness due to compounding factors, such as increased medical costs and limited ability to keep working due to AIDS, mental illness, and substance abuse. While panel members considered this to be an important indicator of need, members acknowledged the difficulty involved in accurately measuring homelessness. Following is a discussion of the two variables related to homelessness considered by the group.

People without conventional housing: The U.S. Census creates a measure of the population without conventional housing that is separated into the total housed in institutions and group quarters and those in what is called transitional and emergency shelters. This category includes shelters for children who are runaways, neglected, or without conventional housing; transitional shelters for people without conventional housing; and hotels and motels used to provide shelter for people without conventional housing. It does not include people enumerated at shelters for abused women (or shelters against domestic violence), transitional housing, and permanent supportive housing.

Although the workgroup was interested in using these data, the Census urged against interpreting these results as a count of the homeless population because they felt that the measurement of the data created biases that could vary dramatically from place to place. Specifically, the Census cautions against using these numbers as an estimate of the homeless population for the following reasons (see Smith and Smith, 2001, for additional details):

- The numbers reflect a one-time assessment of centers that by nature change in population dynamically and dramatically with time.
- Definitions of homelessness differ between localities. Furthermore, counts obtained at assessment sites will depend on the weather the day the count was taken, the bureaucratic policies and police practices of the jurisdiction, and the availability of shelters.
- Many important centers, such as drop-in centers and health care facilities, were not included in the assessment.
- People residing in abandoned property were not counted.
- People who physically moved from one place to another during the evening of the counts were not counted.

The workgroup followed the Census recommendation that this measure was not a valid measure of homelessness and did not forward this variable for inclusion in an SON index. However, the workgroup urged consideration of this variable in the future in the event that new data measuring homelessness and services for the homeless are identified.

Group		Item	Example
Descriptive Characteristics		Variable Name	Health Infrastructure System – Homeless (people without conventional housing)
		Data Element	National estimate of people without conventional housing
		Source	Emergency and Transitional Shelter Population
		Rationale	Indication of homelessness (people without conventional housing, who are at high need for CARE Act services)
		Type of Measure	Proxy measure of homelessness
		Level of Aggregation	County
		Frequency of Updates	2000 Census
		Cost	Free
		Availability	U.S. Census Bureau; public domain; available at: http://www.census.gov/population/www/cen2000/phc-t12.html
Quality and Fidelity		Reliability	Assessed "fair" reliability/quality, measured with great uncertainty in many areas.
		Validity	Census does not consider this variable a valid measure of homelessness. See link for limitations: http://www.census.gov/prod/2001pubs/censr01-2.pdf.
		Bias from Measurement Error	Counts of homeless may very dramatically from place to place depending on the weather the night the count was taken, bureaucratic and police policies towards the homeless, and the availability of shelters. A probabilistic sampling frame, and surveying strategy to represent that frame would need to be created to obtain an accurate estimate of the homeless.
		Adjustments	No

Group	Item	Example
	Possible	
	Usability	No
	Burden	No
Worth	Inclusion	No. However, homelessness should be included in an SON index in the event an accurate measure of the homeless population is developed.
	Weight	Not applicable

Availability of service centers for the homeless: The panel identified one potential source of data on services available to the homeless, the 1996 National Survey of Homeless Assistance Providers and Clients (NSHAPC). After review, these data were determined to be too old and of too uncertain quality to use in a current SON index for resource allocation purposes. However, the workgroup urged consideration of this variable in the future in the event that new data measuring homelessness and services for the homeless are identified.

Group	Item	Example
Descriptive Characteristics	Variable Name	Availability of Service Centers for the Homeless
	Data Element	Estimate of homeless assistance providers
	Source	NSHAPC
	Rationale	Indication of homelessness
	Type of Measure	Proxy measure of homelessness
	Level of Aggregation	Person and metropolitan statistical area (MSA)
	Frequency of Updates	Survey conducted in 1996
	Cost	Free
	Availability	U.S. Census Bureau; public domain; available at: http://www.census.gov/prod/www/nshapc/HSHAPC4.html
Quality and Fidelity	Reliability	Assessed "fair" reliability/quality
	Validity	Limited measure of homelessness. See link for limitations: http://www.huduswer.org/publications/homeless/homelessness/ch_1e.html.
	Bias from Measurement Error	Error is across the board
	Adjustments Possible	No
	Usability	No
	Burden	No
Worth	Inclusion	No
	Weight	Not applicable

C. Poverty and Census

Variables considered: population, percent uninsured, percent unemployed, median household income, percentage below 100 percent Federal poverty level, percentage below 200 percent Federal poverty level, cost of living adjustment using locality adjustments, cost of living adjustment using CPI regional indexes, percent with other insurance, percent underinsured

Poverty may be related to resource needs for CARE Act services in several ways. The poor are more likely to lack health insurance than the wealthy, and therefore poor areas might require greater Federal assistance to provide adequate care for their HIV patients. For those infected with HIV, the poor experience a higher risk of death than more affluent patients (Cunningham et al., 2005) and are less likely to respond to antiviral medications (probably due to poorer rates of adherence to therapy) than the affluent (Anastos et al., 2005). In fact, a recent study found no differences in health outcomes between HIV-infected patients once income and other variables were accounted for (Anastos et al., 2005). Poverty also may serve as a proxy measure for undiagnosed cases of HIV.

The workgroup discussed a large number of Census variables that could measure poverty. These variables essentially can be divided into those whose interpretation depends to some degree on the cost of living, those whose interpretation is independent of the cost of living independent, and variables that define the cost of living in each area. The majority of workgroup discussions revolved around potential possibilities to adjust poverty information to account for differences in the standard of living across areas. After investigation, the workgroup decided that the present data were inadequate to adjust poverty statistics in such a manner. However, the group felt strongly that the poverty and income measures should be adjusted in future indexes in the event the U.S. Census develops an accepted methodology for doing so.

1. Variables forwarded for consideration

Percentage below 100 percent Federal poverty level:

Census-based measures of poverty can serve as geographic indicators of areas with substantial need. Poverty is thought to relate to HIV resource needs because poor patients are less likely to receive an early diagnosis of their infections, are less adherent to therapies once diagnosed, and have worse health outcomes following diagnosis than more affluent patients. Ideally, an SON index would measure poverty among HIV infected patients. However, the area level poverty measure is likely a somewhat adequate proxy measure for individual-level poverty in the absence of such data.

Poverty is defined as the percentage of people living below a certain income level, defined nationally and equal for all jurisdictions. This is potentially problematic because in areas with high costs of living many individuals may be functionally impoverished without qualifying as being in poverty under Federal guidelines. Also, because social programs, particularly Medicaid, are tied to poverty levels, very poor citizens may in many cases have better health insurance coverage than families struggling just above the poverty line.

One hundred percent of poverty was forwarded for consideration in accordance with the charge to the panel to develop measures for the allocation of Title I supplemental funds. The panel

considered whether the variable *percentage below 200 percent of poverty,* which is only available at the State level*, should be used to allocate Title II funds. The 200 percent of poverty measure might potentially measure areas with a large number of working poor who may not be eligible for State Medicaid and would therefore need to rely on the CARE Act. The panelists recommended that *200 percent of poverty* be considered for the allocation of Title II funds if its variance is demonstrated to meaningfully vary from the 100 percent of poverty measure.

Group	Item	Example
Descriptive Characteristics	Variable Name	Poverty Rate
	Data Element	Census Bureau estimates of the percentage of people in poverty; the Census Bureau's Small Area Income and Poverty Estimates (SAIPE) Program. These are model-based estimates based on the Annual Social and Economic Supplement to the Current Population Survey, Census 2000, and administrative data.
	Source	US Census Bureau.
	Rationale	A geographic measure can serve as an indicator of individual resource needs when individual-level data are unavailable or infeasible to collect.
	Type of Measure	Model-based estimate of poverty
	Level of Aggregation	County
	Frequency of Updates	Annual: estimates are released each fall (for example, figures for calendar year 2003 were released in November 2005).
	Cost	Free
	Availability	Public domain
Quality and Fidelity	Reliability	The Census Bureau's SAIPE Program is well established, with a methodology that has been reviewed by a National Academy of Sciences (NAS) panel. Poverty estimates from this program are used to allocate billions of dollars annually under the Department of Education's Title I Program.
	Validity	Yes, generally. The poverty rate is one of the Federal Government's key measures of economic need, although it has several well-recognized limitations (for example, thresholds have not been updated except for inflation adjustments for over 20 years, the definition of income used to define poverty is limited and does not include the effect of noncash benefits, and poverty thresholds do not vary by geographic area). Also, as a survey-based measure, undercoverage and underreporting of income (common to all income surveys) have an effect on the estimates.
	Bias from Measurement Error	Although there are several sources of bias that could have an impact, the effect is unknown. The conventional wisdom has been that the effect of income underreporting is larger at the upper end of the income distribution than at the lower end, but no one really knows the impact of underreporting on poverty rates and whether it varies by jurisdiction. Similarly, there are no known estimates of poverty available at the county level based on thresholds that have been adjusted based on differences in the cost of living by area.
	Adjustments Possible	None
	Usability	No
	Burden	No

Worth	Inclusion	Yes, either as a stand-alone variable or combined with other variables to develop a composite index of poverty
	Weight	No specific weight recommended

Percent uninsured: Percent uninsured measures the percentage of the population with no health insurance. The percent uninsured measure is only available at the State level of aggregation. Lack of insurance is important in understanding resource needs for CARE Act services because the CARE Act is the so-called payer of last resort. The greater the percentage of the population with no insurance, the more likely is the need for the CARE Act. As with the poverty variable, percent uninsured is measured at the population level and not among individual HIV-infected patients. A preferable future measure would be the percent of HIV-infected patients with no insurance, as this rate might differ from the overall population average. However, unlike the poverty measure, percent uninsured is not distorted by differences in cost of living.

Percent uninsured does not capture patients who are underinsured, and so by itself the variable does not capture accurately all patients who may need the CARE Act. HIV-positive patients who hold private insurance may need additional services from the CARE Act for which their insurance does not pay. For example, many patients who are "insured" hold only coverage for inpatient episodes or lack coverage for prescription drugs. Also, publicly insured patients may require additional assistance from the CARE Act in States with less generous Medicaid programs.

Group	Item	Example
Descriptive Characteristics	Variable Name	Health Insurance Coverage – Percent Uninsured
	Data Element	Percent uninsured (3-year average)
	Source	U.S. Census Bureau, Current Population Survey, Annual Social and Economic Supplement: http://www.census.gov/hhes/www/hlthins/historic/
	Rationale	The uninsured rate of an area may be an important indicator of differences in HIV/AIDS-related resources/needs. A geographic measure can serve as an indicator of individual resource needs when individual-level data are unavailable or infeasible to collect.
	Type of Measure	Direct
	Level of Aggregation	State
	Frequency of Updates	Annual
	Cost	Free
	Availability	Public Domain

Quality and Fidelity	Reliability	The Census Bureau employs quality control procedures in survey design, training and performance of interviewers and coders, and statistical review of data results. Sampling variability for State estimates can be high and can fluctuate widely year to year. To improve estimates, the Census Bureau uses and recommends using 3-year averages to compare estimates across States.	
	Validity	Yes, generally. Underreporting of coverage is likely, but the percentage is probably consistent across States/Regions.	
	Bias from Measurement Error	Health insurance coverage is likely to be underreported in any survey, and this bias appears to be a larger problem in the Current Population Survey (CPS) Annual and Social Economic Supplement (ASES) than for other national surveys that collect insurance information. ASES underreports Medicare and Medicaid coverage compared with enrollment and participation data from the Centers for Medicare & Medicaid Services.	
	Adjustments Possible	CPS weighting procedure (sample estimates are adjusted to independent estimates of the national population by age, race, sex, and Hispanic origin) corrects for bias due to undercoverage.	
	Usability	No	
	Burden	No	
Worth	Inclusion	Yes, moving 3-year averages. To be used either as a stand-alone variable or combined with other variables to develop a composite index of poverty.	
	Weight	No specific weight recommended	

Population: Population is a variable needed to construct rates of other variables. It is not itself a measure of SON.

Group	Item	Example
Descriptive Characteristics	Variable Name	Poverty – population – total population, and population by age, sex, race, and Hispanic origin
	Data Element	Census Bureau estimates of population, by county
	Source	The Census Bureau's Population Estimate Program
	Rationale	The population of an area is a key denominator variable in determining funding levels and eligibility; and the population of an area by selected characteristic can be a valuable indicator of differences in resource/needs.
	Type of Measure	Estimates
	Level of Aggregation	County
	Frequency of Updates	Annual – estimates of total population by county are released in the spring (July 1, 2004, county estimates were released in April 2005). Estimates by county population by characteristic are released later in the year.
	Cost	Free
	Availability	Public domain
Quality and Fidelity	Reliability	This is likely the most reliable measure collected by the U.S. Census.
	Validity	Population estimates exclude undocumented aliens, and the number of those aliens varies substantially by area.

Group		Item	Example
		Bias from Measurement Error	Areas with greater numbers of undocumented aliens will have a lower proportion of their true population counted than areas with fewer undocumented aliens.
		Adjustments Possible	None
		Usability	No
		Burden	No
	Worth	Inclusion	Yes, in combination with other variables
		Weight	Population should not itself be considered an indicator of SON.

2. Variables not forwarded for consideration

Percentage below 200 percent Federal poverty level: The workgroup investigated using the percent of the population living below 200 percent of the Federal poverty level as a more expansive definition of poverty than the percent living below 100 percent of the Federal poverty level. Potentially, using this more expansive definition would in part compensate for lack of adjustments for large differences in cost of living from area to area. The U.S. Census collects measures of 200 percent of poverty data at the county level once every 10 years. Some, privately created measures of 200 percent of poverty at the State level exist and are updated with greater frequency. The measure *percentage below 100 percent of poverty* was forwarded for consideration in accordance with the charge to the panel to develop measures for the allocation of Title I supplemental funds, since it is the only measure of poverty that is available annually at the county level. Some panelists considered *percentage below 200 percent of poverty* to be a more expansive definition of poverty and perhaps a better indicator of need for CARE Act resources for the working poor who are uninsured or underinsured. If the SON index were to be extended beyond Title I and proposed for use in allocating Title II resources, the variable *percentage below 200 percent of poverty* should be considered.

Group		Item	Example
		Variable Name	Poverty – Percentage under 200% of poverty
	Descriptive Characteristics	Data Element	Census Bureau estimates of the percentage of people in families with incomes under 200% of their poverty threshold
		Source	The CPS ASES
		Rationale	A geographic measure can serve as an indicator of individual resource needs when individual-level data are unavailable or infeasible to collect.
		Type of Measure	Survey estimate
		Level of Aggregation	State County – once every 10 years
		Frequency of Updates	Annual: CPS estimates are released in August of each year
		Cost	Free
		Availability	Public domain

		Reliability	Moderate. State estimates from CPS have relatively large sampling errors. Therefore, the Census Bureau recommends using 3-year averages to moderate their impact.
		Validity	Yes, generally. This statistic has the same basic validity issues as the poverty rate. Poverty-related measures are among the Federal Government's key measures of economic need, although they have several well-recognized limitations (for example, thresholds have not been updated except for inflation adjustments for over 20 years, the definition of income used to define poverty is limited and does not include the effect of noncash benefits, and poverty thresholds do not vary by geographic area). Also, as a survey-based measure, undercoverage and underreporting of income (common to all income surveys) have an effect on the estimates.
Quality and Fidelity		Bias from Measurement Error	Although there are several sources of bias that could have an impact, the effect is unknown. The conventional wisdom has been that the effect of income underreporting is larger at the upper end of the income distribution than at the lower end, but no one really knows the impact of underreporting on poverty-related measures and whether the impact varies by characteristic.
		Adjustments Possible	None
		Usability	No
		Burden	No
Worth		Inclusion	No. Data related to those under 100% of the Federal poverty level are available from the Census Bureau at the county level annually. Data related to those under 200% of the Federal poverty level are available at the county level with less frequency and are available annually only at the State level. As a result, *percentage below 100% of poverty* is the better measure for an index that will be used to allocate funds at the county and multi-county levels. However, if the SON index were extended beyond Title I and were proposed for the allocation of Title II funds, the variable *percentage below 200% of poverty* should be considered, since data are available annually at the State level, and since this variable might be a more expansive definition of poverty and might be a better indicator of need for CARE Act resources for the working poor who are uninsured and underinsured.
		Weight	N/A

Percent unemployed: Population rates of unemployment represent an alternative measure of poverty. As with the poverty rate and the uninsured rate, the variable measures unemployment in the entire area. A preferable, but currently unavailable, measure would be unemployment among HIV-infected patients. Like the uninsured rate, the interpretation of the unemployment rate is not affected by differences in the cost of living.

The mixed-group panel discussed the list of economic indicators recommended by the group. They felt that of the three (poverty, median income, unemployment), unemployment likely would be duplicative of other measures and suggested its exclusion.

Group	Item	Example
Descriptive Characteristics	Variable Name	Unemployment
	Data Element	Total people unemployed and unemployment rate
	Source	Bureau of Labor Statistics, Local Area Unemployment Statistics (LAUS) program: http://www.gls.gov/lau
	Rationale	The unemployment rate of an area may be an important indicator of differences in HIV/AIDS-related resources/needs. A geographic measure can serve as an indicator of individual resource needs when individual-level data are unavailable or infeasible to collect.
	Type of Measure	Direct
	Level of Aggregation	County (MSAs, States, Census regions, and divisions)
	Frequency of Updates	Monthly and annually
	Cost	Free
	Availability	Public domain
Quality and Fidelity	Reliability	Good; concepts and definitions underlying the LAUS data come from the CPS. Methodology is consistent across States. State monthly model estimates combine data from CPS, the Current Employment Statistics program, and State unemployment insurance systems.
	Validity	May underestimate unemployment in rural areas; may overestimate unemployment in areas with larger underground economy
	Bias from Measurement Error	Bias against rural areas where State employment offices may be few and far between. Does not compare employment in the underground economy.
	Adjustments Possible	No
	Usability	No
	Burden	No
Worth	Inclusion	No
	Weight	N/A

Median household income: Median household income defines the income value directly in the center of the income distribution for an area. Median income may serve as an additional indicator of poverty or need for services because areas with very low median incomes may require additional assistance from the CARE Act. As with other aggregate measures, median income measures the middle income value of all households in an area, not the median income of HIV-infected patients. The interpretation of median income is affected by differences in cost of living from area to area. After further discussion, the panel declined to forward this variable for consideration, arguing that without an adjustment for cost of living, median income would not likely meaningfully explain a unique component of resource needs.

Group	Item	Example
Descriptive Characteristics	Variable Name	Median Household Income
	Data Element	Census Bureau estimates of medial household income
	Source	The Census Bureau's SAIPE Program. These estimates are based on the Annual Social and Economic Supplemental to the CPS, Census 2000, and administrative data.
	Rationale	A geographic measure can serve as an indicator of individual resource needs when individual-level data are unavailable or infeasible to collect.
	Type of Measure	Model-based
	Level of Aggregation	County
	Frequency of Updates	Annual-estimates are released each fall (for example, figures for calendar year 2003 were released in November 2005).
	Cost	Free
	Availability	Public Domain
Quality and Fidelity	Reliability	Yes, the Census Bureau's SAIPE Program is well established, with a methodology that has been reviewed by an NAS panel. Estimates from this program are used to allocate billions of dollars annually under the Department of Education's Title I Program.
	Validity	Yes, generally. The main validity issues with the income figures are that (1) they are based on money income alone and do not include the effect of noncash benefits, and (2) the estimates are not adjusted for geographic differences in the cost of living. Also, as a survey-based measure, undercoverage and underreporting of income (common to all income surveys) have an effect on the estimates.
	Bias from Measurement Error	Although there are several sources of bias that could have an impact, the effect is unknown. National experimental estimates are available that use a broader definition of income that includes the effect of noncash benefits and taxes, but these estimates are not available at the county level. Also, while underreporting of income certainly has an impact, the effect on national and subnational median household income estimates is unknown.
	Adjustments Possible	An adjustment for differences in cost of living is essential. Adjusting this figure for differences in cost of living would be desirable. However, no standardized method for doing so exists at this time (see below).
	Usability	No
	Burden	No
Worth	Inclusion	No
	Weight	No specific weight recommended

Cost of living adjustment using locality adjustments: The workgroup investigated ways to adjust poverty variables to account for differences in cost of living across jurisdictions. One such potential adjustment was to use Federal pay scale locality adjustments. Federal pay locality adjustments adjust the Federal salary paid to employees in certain areas based on the directly

observed purchase price of different goods and services. However, adjustments are only available for 32 areas nationwide, and no adjustments are available for low cost areas. Also, wide differences in cost of living exist within areas that have adjustments. The workgroup recommended not including this variable and waiting for the U.S. Census to develop a methodology to adjust dollar-based estimates to account for cost of living differences.

Group	Item	Example
Descriptive Characteristics	Variable Name	Cost of living
	Data Element	Federal Pay Locality Adjustments
	Source	U.S. Office of Personnel Management: http://www.opm.gov/oca/05tables/txt/gstbls.txt
	Rationale	Certain areas may be more costly to live in than others, and these areas might require more resources to provide the same level of care.
	Type of Measure	Direct measure of cost-of-living
	Level of Aggregation	32 specific locality pay areas, which are essentially big MSAs
	Frequency of Updates	Annually
	Cost	Free
	Availability	Public domain
Quality and Fidelity	Reliability	Good. Index is based on the directly observed purchase price of different goods and services.
	Validity	Average. Locality adjustments are good for high-cost areas of the country but areas not included in a locality pay area have no adjustment. Therefore, low-cost areas are assumed to have the same as average cost. All counties included in a single locality may not have the same costs.
	Bias from Measurement Error	None
	Adjustments Possible	Potentially, this measure could be adjusted in one of several ways. All counties could be assigned to one of the Federal localities or an average of two or more localities if they are geographically between them. This measure could be combined with BLS estimates of regional costs for urban/suburban/rural in different regions of the country, although it is unclear if those indexes can be compared across regions or only measure price changes within region. Values could be dichotomized to (0/1) to indicate high-cost areas. All counties in high-cost areas can then be given a similar "high-cost" weight in a resource allocation algorithm.
	Usability	Counties with no locality adjustment might argue that cost of living is not adequately measured for their jurisdiction.
	Burden	None
Worth	Inclusion	No
	Weight	Not applicable

Cost of living adjustment using regional CPIs: The Bureau of Labor Statistics produces 27 regional CPIs. However, these regional indexes cannot be used to measure differences in price levels or living costs between one place and another; it measures only time-to-time changes in each place. A higher index for one area does not necessarily mean that prices are higher there than in another area with a lower index. It merely means that prices have risen faster since the two areas common reference period. The panel determined that this information was not necessary for an SON index.

Group	Item	Example
Descriptive Characteristics	Variable Name	Cost of living
	Data Element	Consumer Price Index – 27 regional Indexes
	Source	Bureau of Labor Statistics: http://www.opm.gov/oca/05tables/txt/gstbls.txt
	Rationale	More costly areas may require greater resources. Understanding how costly an area is may be important in understanding an area's poverty statistic. Areas experiencing rapid increases in prices may require greater resources.
	Type of Measure	Measure cost of living in an area compared to earlier years
	Level of Aggregation	27 areas
	Frequency of Updates	First group: every month; second group: every other month; third group: every 6 months
	Cost	Free
	Availability	Access can be obtained through directions found under the "Electronic access to CPI Data" heading at http://www.bls.gov/epi/cpifaq/htm.
Quality and Fidelity	Reliability	Excellent within area. Sampling error can be overcome by averaging several consecutive estimates.
	Validity	Limitations of application. CPI cannot be used to measure differences in price levels or living costs between one place and another; it measures only time-to-time changes in each place. A higher index for one area does not necessarily mean that prices are higher there than in another area with a lower index. It merely means that prices have risen faster since the two areas common reference period.
	Bias from Measurement Error	No
	Adjustments Possible	No
	Usability	No
	Burden	No
Worth	Inclusion	No
	Weight	Not applicable

Percent underinsured: The panel considered the need to evaluate the percentage of the population that lacked adequate insurance in addition to the percentage with no insurance. A lack of adequate insurance could indicate a need for CARE Act to pay for outpatient or prescription drug services. However, no such measure at the State level exists. "Underinsured" is generally

defined as being insured but also having annual out-of-pocket medical expenditures that exceed 10 percent of annual income. Currently, there is no national survey that can be used to make reliable county or State underinsured estimates for all 50 States. CPS collects income and health insurance data and is large enough to produce State estimates, but it does not collect medical expenditure data. Conversely; the Medical Expenditure Panel Survey (MEPS) collects health insurance, income, and medical expenditure data, but the sample is relatively small and it cannot produce State or county estimates.

Group	Item	Example
Descriptive Characteristics	Variable Name	Health Insurance – Underinsured Rate
	Data Element	Underinsured rate
	Source	None. "Underinsured" is generally defined as being insured but also having annual out-of-pocket medical expenditures that exceed 10% of annual income. Currently, there is no national survey that can be used to make reliable county or State underinsured estimates for all 50 States. CPS collects income and health insurance data and is large enough to produce State estimates, but it does not collect medical expenditure data. Conversely, MEPS collects health insurance, income, and medical expenditure data, but the sample is relatively small and it cannot produce State or county estimates.
	Rationale	The underinsured rate of an area may be an important indicator of differences in HIV/AIDS -related resource/needs. A geographic measure can serve as an indicator of individual resource needs when individual-level data are unavailable or infeasible to collect.
	Type of Measure	N/A
	Level of Aggregation	County or State
	Frequency of Updates	N/A
	Cost	N/A
	Availability	N/A
Quality and Fidelity	Reliability	N/A
	Validity	N/A
	Bias from Measurement Error	N/A
	Adjustments Possible	N/A
	Usability	N/A
	Burden	N/A
Worth	Inclusion	No
	Weight	N/A

Personal Income: Personal income represents a measure of the total accumulated new wealth in an area in a given year. It can be represented as either a total value or a per capita rate. The workgroup investigated personal income as a measure of resources that could potentially be marshaled to support HIV/AIDS services. A potential rationale for its inclusion is that, all other

variables held equal, an area with greater personal income would have a higher capacity to care for its own HIV/AIDS patients. However, the panel felt that personal income did not represent the wealth available to health policy makers to provide for HIV/AIDS patients. They were concerned that its inclusion could penalize HIV-infected patients living in affluent but indifferent areas. Also, indigent HIV/AIDS patient likely have very little power to influence how areas spend their wealth, so penalizing affluent areas that spend little to care for their HIV/AIDS populations is likely to have little impact on those allocating funding but potentially devastating effects on those who need service.

Group	Item	Example
Descriptive Characteristics	Variable Name	Area resources
	Data Element	Personal income (total and/or per capita)
	Source	U.S. Bureau of Economic Analysis http://www.bea.doc.gov/bea/regional/reis/ Description: Personal income is the income that is received by persons from participation in production, from both government and business transfer payments, and from government interest (which is treated like a transfer payment). It is calculated as the sum of wage and salary disbursements, other labor income, proprietors' income with inventory valuation and capital consumption adjustments, rental income of persons with capital consumption adjustment, personal dividend income, personal interest income, transfer payments to persons, and less personal contributions for social insurance.
	Rationale	This variable measures the amount of income in an area. Possibly, this income could be used to support HIV/AIDS services. It provides a measure of the ability of an area to pay for services in several ways: (1) it demonstrates the size of the income tax base in a State, and (2) it serves as a proxy for individual resources such as private insurance. However, the variable does not measure an area's willingness to pay for HIV/AIDS services or reflect its actual contributions to those services.
	Type of Measure	Direct
	Level of Aggregation	State and MSA
	Frequency of Updates	Quarterly or annual
	Cost	Free
	Availability	Public domain
Quality and Fidelity	Reliability	Yes
	Validity	Federal agencies use these estimates in econometric models, such as those used to project energy and water use. In addition, as part of its program for SAIPE, the Census Bureau uses the estimates of county per capita personal income as a predictor variable in the preparation of its county estimates of median household income. The SAIPE program provides updated estimates of income and poverty statistics for the administration of Federal programs and the allocation of Federal funds to local jurisdictions.
	Bias from Measurement Error	No
	Adjustments	No

	Possible	
	Usability	No
	Burden	No
Worth	Inclusion	No. The combined panel felt that personal income did not measure income available to HIV service providers to care for patients.
	Weight	N/A

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III. History of the Panel

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